Raising Two Fingers

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In *A Sense of Self*, Camerawork, 1988
Accompanied *Sense of Self*, the first exhibition of photo-images of disabled people controlled by disabled sitters, Camerawork, London, July-August 1988

What I am aiming to do is provide some of the background thinking which may have taken place for some of the sitters before and during their involvement with the exhibition. Whilst it is important to recognise that the experiences represented are one person's, I found that I travelled through several distinct stages which I believe are broadly common to many disabled people.

Stage 1 – able-bodied
Stage 2 – pseudo able-bodied/ injured able-bodied
Stage 3 – disabled – as defined by the able-bodied world
Stage 4 – disabled – as defined by *self*.

It is with this fourth stage that *Sense of Self* is primarily concerned. But this stage exists as a result of struggling through (and surviving!) some or all of the previous stages.

I was born able-bodied, and my self image was never questioned. I was never required to make my self-identity overt because the whole structure of the able-bodied world automatically endorsed it.

At the age of ten, things began to change, following injury. By this time I was well-indoctrinated into the able-bodied world, and it took a lot to make me question that I could be anything other than able-bodied. In the absence of diagnosis, I was able to kid myself for a long time that in fact I was still able-bodied and, if I waited just a little longer, I would be cured.

As my impairment continued and increased, it became gradually more obvious my world was not going to return peacefully to its familiar able-bodied mould.

> I can't really get on with living as long as I'm searching for a Cure, as long as a little bit of me is constantly hoping to be different from the way I cam now. Everyone is so concerned with Cure – whether it's family wanting 'what's best', or total strangers, doctors, the media, talking of tragedies and miracle cures and 'have you tried…?"
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> I believe I'm not actually looking for a Cure any longer; or at least it is now not a priority for me. But to be constantly searching to be different is not

> only exhausting, but negates what I am. I have to live for the present as well as the future.

As my needs increased and my surroundings became more and more inaccessible to me, the able-bodied world which had previously embraced me now rejected me.

> The rejections came in all shapes and sizes, from the charming and apologetic to the downright rude.
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> I can't do *anything* – no one will *let* me do anything.

I was no longer able to fit my society's norms, so I was deemed 'disabled'. On investigating the newly assigned categorisation, I found it far from desirable. The message given was that disabled people did not function as 'other' 'normal' people did; they were fully reliant on able-bodied people, they were incapable of controlling their own lives – in all, disability was the ultimate tragedy, to be avoided – stay able-bodied at all costs. The message was all about 'they'; I would not identify with this alien group and had no wish to enter it.

> They discussed their views on sickness. If one of the family falls ill, they are ignored until they are better. Illness is a sign of human weakness, of failure.
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> According to my GP, I don't look like an 'invalid' and mobility allowance criteria are so strict that "they only ever award it to people who are too bad to be out anyway".

As my impairment because established, I made a brief foray into defining myself as disabled, but the reactions of people around me discouraged further attempts.

> I told him on Saturday about getting the chair. He went kind of red-in-the-face and began asking all sorts of awkward questions, like he always does when he doesn't want to be pushed into expressing an opinion, such as "Well who's going to push you?" And I just thought, Oh God, this is going to be awful.
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> There's no one to relieve my shock: no support, no counselling, nothing. All the burden rests on me. It's my decision and so I supposedly don't feel the pain. I'm supposed to remain detached, unaffected.

Instead, it seemed preferable to stay able-bodied at all costs. For years I made passable attempts, bolstered by those people closest to me who would not wish upon me that fact-worse-than-death.

It did cost me. I was bundled repeatedly and unceremoniously between the two camps, by all those involved in my little drama. My needs were pronounced 'special' from on high and so I was clearly too disabled to be able-bodied, and yet my needs were not believed 'special' enough to qualify for disabled status and the provision I required. In all this, it was fairly obvious to anyone appropriately motivated what my needs were and how simply they could be met, but with all sides disputing my identity, I became enmeshed in the archetypal 'Catch 22'.

> I'm definitely not able-bodied. Yet not do I fit their description of disabled. What does that make me? An aberrant cripple? What an identity crisis!
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> I felt so powerless. Overnight he demolished my life and all I could do was raise two fingers to his door, which I did repeatedly. Is that the full extent of retribution?

The dilemma was further complicated. Throughout, neither my family not I received any acknowledgement from medics that they did not know the cause of my increasing pain, did not understand its progressive nature and could not forecast its future.

Lack of diagnosis was apparently an indication that I was malingering, attention-seeking, introverted – in all, unable to cope with the demands of the modern world. Clearly I was not disabled, but my status as malingerer also served to exclude me from the privileged ranks of able-bodiedom. This time I was left in some sort of Nowhere Land.

> I can't tell the doctor I'm depressed because it will all go down on record and I've seen how easily it can be used against me. Let's be honest – they'll hardly offer a place on the course to a clinically-depressed, suicidally-tendancied, disabled female!
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> I'm told I'm not an arthritic, an epileptic, a spastic, a dyslexic, nor even, it appears, a hypochondriac. So that whilst I partially escape being dehumanised by these labels, so too do I miss life being partially humanised by the services which exist for people so defined. But he did admit that I didn't seem like 'an hysteric' and, if only if weren't all psychological, he'd be congratulating me on how well I had adapted. Work that one out!

There is a theory in psychology that if you are told things loud and long enough, you adopt them. I don't know that I demonstrated all the characteristics attributed by the professionals (many of which were severely contradictory anyway), but certainly during my teens I learned to fear meeting people and having to expose the fact that 'I was not coping'. I no longer wore the bright colours that suited me, but instead turned to fawns and greys and was partially successful at merging into my surroundings.

Invisibility naturally became more difficult as I became visibly disabled. Yet, even through this, all photographs of me bar one conveniently exclude my wheelchair from the viewfinder. Is it an attempt to make me believe everything is OK really, or to hide the truth from strangers, or is it for other people's dreamed-of future when I will be able-bodied once more and all of this can be relegated to a little box marked 'nightmares'?

Staying able-bodied meant denying my needs (trying to write instead of using a word processor), meant pretending not to be in pain (giving up hot water bottles, splints, slings; meant holding myself like an able-bodied person), meant experiencing more pain than was necessary (carrying on, never giving up, no matter how painful), meant my education suffered (trying to concentrate amidst elevated pain and not being able to keep pace with able-bodied writing), meant losing my social life (having to catch up on school work whilst my friends enjoyed themselves). I tried, but it was bound to fail. There was no chance!

> My chronic pain is a part of me – it isn't something I can reject. I know every time I say I can't do something, I am the only one it hurts, and yet there are things I can't do, limits beyond which I can't push myself.
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> One of the books was on chronic pain – it's the latest trend in medical books, written by doctors who clearly have little or no experience of pain. They all have emotive titles like 'conquering' or 'overcoming' in their titles. According to the latest publication, we should renounce all medication, all other aids which relieve pain, all non-verbal communication regarding pain, all verbal communication regarding pain, all alternative ways of doing things (like rising from a chair differently), all cancellations of engagements because of pain. In other words, at all costs, *deny* your disability.
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> We talked about my wheelchair and she told me how at first she was very upset, still is, but now differently; how one night she lay awake analysing *why* she felt upset and realised it was for all the wrong reasons – parental aspirations, etc - and that deep down she was feeling all the able-bodied assumptions, you know, tragedy, loss of ability, looks, independence, you name it. And then she realised that my getting a wheelchair was actually going to provide the means for me to retain/attempt/achieve all those things, and that denying my need would be preventing me from this 'normality'.

During this time, I knew no disabled people on equal terms. The people around me – family, friends, medics, teachers – all were able-bodied. The message I received was that everyone else was able-bodied, they all coped, I was the problem, and it was I who was required to adapt.

> He gave me the chance to explain why and why my decision is more positive than negative. I told him how I was dreading telling everyone else because of their reaction, because of hurting them. He says it's their problem, which I guess is true.

I saw few images of disability. Those that existed made a strong impression on me, strengthening my resolve that at all costs I would not be like 'them'. Charity posters (like Mencap's Little Stephen with tear rolling down cheek, or the kid with muscular dystrophy abandoned with wheelchair in the centre of wasteland), Badges of Fortitude in the Girl Guides or Children of Courage on the TV, *Treasure Island* or *Heidi* with Captain Hook or little Clara, prayers to heal the sick in assembly (and to give thanks that 'but for the grace…'), international years and flag days – all led me to the same reaction: "I'm not like that".

> As far as the railway guard was concerned, we're all flaming saints and martyrs. He told me tales of his Invalid Passengers – the man with the wooden leg and the old lady with arthritis who will not use a wheelchair and takes 35 minutes to get from the ticket office to platform 1. He told me too of the Inner Strength we all possess – the extra patience with which we are endowed. It's amazing – it lets them get away with murder. With all our divine Gifts, why should there be any onus on them to change?
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> I was sitting on a street corner waiting for J, when a man came up to me and attempted to offer me money. (I know there's a slot in my head somewhere.) Talking to friends, I discovered that it's not an unusual experience – they had been offered fifty pences and ten-pound notes. I was mortified to realise I had only been worth ten pence.
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> I use to get plenty of wolf whistles as a teenager (for all I feel about wolf whistles). Then I got my chair. I've had only one wolf whistle since, and that from a minah bird down the road which has been taught to whistle at every woman who passes. I'm told that asexuality is the rarest form of disability, but it beats me why it is only birds that recognise I'm a woman.

Faced with able-bodied images of disability, it seemed vastly preferable to conform (however inadequately) to the demands of able-bodiedness. I consistently and emphatically rejected any attempts to describe me as disabled, preferring to continue struggling – quietly.

It was fortuitous that my work interests lay in the field of disability. (Rejecting images of disability, however forcefully, did not prevent me from wanting to become involved with disabled people, though firmly in a 'helping' role – was this me desperately staving off further attempts at labelling?). If my interests had been otherwise, I might never have attended the conference organised by my college community action group. Organised by non-disable people (how many disabled people do you find in higher education?), two disabled women were amongst the invited workshop leaders, lending an air of credibility to the proceedings.

Joining their session *Politics of Disability,* it was like a dam burst. Here were two women who identified themselves *willingly* as disabled! Here were two women, disabled and strong. They were unlike all the images fed to me by the able-bodied world. For the first time, I realised that in trying to determine my identity, I had only ever been presented with able-bodied conceptions of able-bodiedness and disability. At last, I realised that other definitions could exist. Like those two disabled women, I could find *my* self and my *self* did not have to exist on able-bodied terms!